IPPR NORTH

REPORT

INCLUSIVE INTEGRATION

HOW WHOLE PERSON CARE CAN WORK FOR ADULTS WITH DISABILITIES

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Institute for Public Policy Research

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SUMMARY

The concept of whole person care is about making the connections between physical health, mental health and social care services, focussed on the needs of an individual. The drive to develop a health service that is fit for the future is firmly grounded in the need to plan for an ageing population. There is a danger, however, that with so much of the focus on the needs of older people, there is insufficient attention given to the distinct needs of other groups of health and care service users.

This report focusses on the needs of working-age disabled adults. There is a risk that this group will be overlooked in the remodelling of services, despite the fact that they make up a large proportion of health and social care service users. A review of existing research highlights that there is much less evidence and data on integrated care outcomes for working-age disabled adults, and current policy interventions, including the Better Care Fund, tend to focus on outcomes for older people.

This is problematic not only because they have different needs and outcomes to older people, but also because working-age disabled adults face more severe and widening health inequalities across all areas of day-to-day life, for example in housing, employment, financial security and quality of life. This report maps out these inequalities in order to demonstrate that closing up health inequalities must go further than simply reforming health and social care services in isolation. To be effective, service integration must be focussed around local patient demographics and the unique needs of service users.

This report maps out 10 dimensions of inequality which affect disabled adults in particular and which threaten to undermine their longer-term health and independence. For example:

- People with disabilities face an average ‘cost of living penalty’ of £550 per month in costs directly attributable to their disability.
- Over a quarter of disabled people say they frequently do not have choice and control over their daily lives.
- They are more likely to live in homes which are inaccessible and have substantial disrepair.
- Despite gains over the past decade, there remains a gap of almost 30 percentage points between the employment rate for people with disabilities and the rate for non-disabled adults.

This report provides an empirical evidence base to demonstrate how whole person care should meet the needs of working age disabled adults. It explores how integrated care outcomes for working-age disabled adults might be formulated to take account of wider health inequalities within a social model of disability. There are real challenges to integrating a health system that is free at the point of delivery with a means-tested social care system. There are also risks to the independence of disabled people if a more ‘medical’ model of the NHS was allowed to predominate over a whole person care approach.

While integration is likely to bring about improved outcomes for patients and users of social care services, evidence concerning cost efficiencies is underdeveloped. There is a huge social care funding gap that needs to be addressed as part of any plan for integrated health and social care – based on council adult social care budgets in 2013/14, this gap is forecast to amount to £1.9 billion by 2015/16.

As part of our research, IPPR North conducted a focus group with 12 disabled adults and carers to gain their views on these issues and on the kinds of outcome they would like to see from the integration of health and social care services[1]. We also undertook interviews with social care and voluntary sector professionals, commissioners and local authority policy leads to get a sense for the appetite to include working-age disabled adults' needs in plans for future integration.

Disabled adults told us they wanted to be recognised as experts in their own care, and to be able to set their own outcomes based around wider measures of wellbeing, such as housing, employment and other needs that sit outside of health and social care in the narrow sense. They wanted to be able to tell their story only once, and to have a single contact for health and social care services. They wanted to experience seamless care, whether from a single provider or multiple organisations, and to be free from the need to be concerned with securing funding for their care.

This report expands on these issues using empirical evidence, and makes a series of recommendations about how whole person care might best take account of the needs of working-age disabled adults.

Key recommendations from the report are:

1. **A long-term view should be taken to managing long-term conditions, and so we recommend that whole person care should be conceived as a 10-year journey, matched by stable funding over this period.** While we recognise that it is not easy for the Treasury to commit funds over the long term, the crisis facing our health and social care system is not going to be fixed by integration in the absence of a long-term financial settlement.
2. **The continuing debate about how to manage the funding gap in social care must take into consideration the needs of working-age disabled adults.** In particular, the funding gap in addressing moderate care needs disadvantages working-age disabled adults, who already face structural challenges, including disparities in employment rates and the cost of living.
3. **Prevention must remain high on the agenda when planning services over the long term.** High-quality care would focus on enabling individuals to manage their own condition in order to slow down its progression or prevent their problems worsening and requiring hospital or residential care.
4. Supporting prevention would be strengthened by shifting resources from case management to community coordinated care. **Disabled people should have a single point of contact for all health and social care needs.** This contact should have responsibility for making sense of complex pathways between services, 'hiding the wiring' from the user, and identifying peer support options to help people understand and manage their conditions.
5. A key frustration for adults with long-term conditions is the sheer number of assessments they must undergo and how often they have to retell their story to public service professionals who are unfamiliar with their circumstances. **For integrated care to best meet the needs of people with disabilities, service integration should take place across a much wider range of services, beyond health and social care**, supported by care coordinators rooted in communities.
6. **Health and wellbeing boards should lead local authorities and clinical commissioning groups in prioritising public engagement across all service user groups.** This is to ensure that progress towards integrated care can be measured according to the demographics of the local area and take into account the needs of a wider range of service user groups, beyond older people alone.

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[1] All quotes in this report are from our focus group participants.

7. **Government should invest in local advocacy projects to support public engagement.** The national Fulfilling Potential Forum established in April 2014 to feed the user's voice into national policymaking should be replicated at the local level, supported by an additional £3 million in funding (equivalent to approximately £20,000 per health and wellbeing board area). We envisage that this investment in self-advocacy could also enable people with disabilities to make representations in other local policy areas, such as city deals.

1.

THE NEED FOR WHOLE PERSON CARE: A PICTURE OF HEALTH INEQUALITIES

By mapping out a broad range of inequalities that impact on working-age disabled adults, we are able to highlight some significant factors driving future ill-health in this group, factors which sit outside of health and social care policies and services in the narrow sense. Poverty, poor connectivity, poor housing conditions, increased costs of living and an employment gap of almost 30 percentage points compared with non-disabled people all contribute to growing health inequalities.

In this chapter, we set out 10 dimensions of inequality affecting people with disabilities. Many of these areas overlap and interact with one other, providing a clearer but more complex picture of the broader factors underpinning the health outcomes of working-age disabled adults. It is evident from the interactions between many of these determining factors that by itself integrating health and social care services will not ensure better care and prevention for this group. Rather, a more progressive long-term approach is needed which draws in housing, financial inclusion, employment and education.

Ten dimensions of disability health inequalities

Health

There are 11.6 million disabled people in Britain, of whom almost half (5.7 million) are working-age adults (aged 18–64) (ODI 2013).

International evidence shows that people with learning disabilities or long-term mental health problems die on average five to 10 years younger than other citizens, often from preventable illnesses.[2] They also have a higher prevalence of obesity and of general ill-health: for example, people with learning disabilities have higher rates of respiratory disease than the remaining population (19.8 per cent versus 15.5 per cent per cent) (Nocon 2006).

There is a broad spatial element to the prevalence of disability, which may also have a bearing on life expectancy. In terms of overall incidence, there is a north/south divide across the English regions, with a higher proportion of people who are limited (a lot or a little) in their day-to-day activities living in the northern regions (figure 1.1). There is also evidence of a north/south divide in terms of disability-free life expectancy – that is, the length of time an individual goes without experiencing ‘a limiting persistent illness or disability’, by their own assessment. Experimental data from the Office for National Statistics (ONS 2014) shows that some people enjoy up to 16 years’ more healthy living (living longer without a disability) in the south than in the north.

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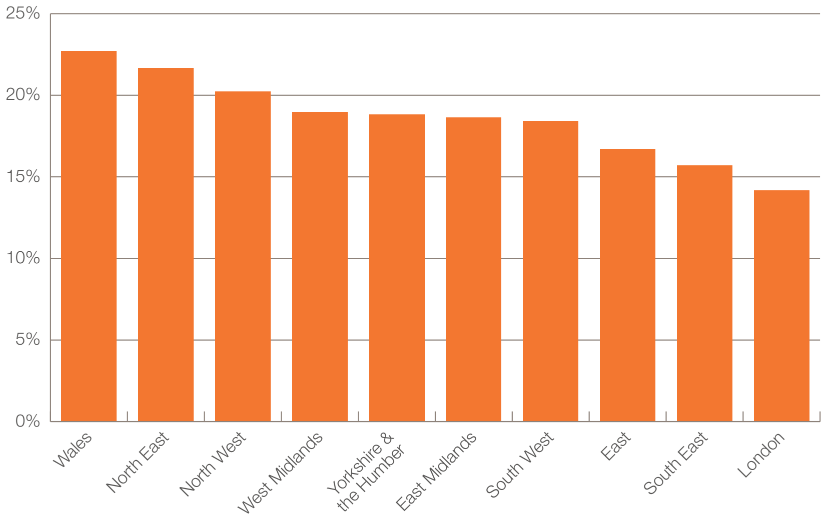
[2] One study in the US found that people with learning disabilities died five years earlier than the rest of the population, while the survival probability for people with learning disabilities in the state of Western Australia was nine years less for men and 10 years less for women (Nocon 2006). The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD 2013) found that men with learning disabilities died, on average, 13 years sooner than men in the general population, and women with learning disabilities died 20 years sooner than women in the general population.

Figure 1.1
Proportion of the population who are limited in daily activities, by region



Source: ONS 2011 Census Analysis, Local Authority Variations in Self-assessed Activity Limitations (Disability) for Males and Females, England and Wales, 2011 (ONS 2013a)
Note: Data represents those who are limited 'a little' or 'a lot' in day-to-day activities.

Financial inclusion and cost of living

Financial inclusion issues impact on the ability of people with disabilities to save and accumulate housing wealth, to access lower insurance premiums, and to access credit. Households with a disabled person are twice as likely as other households to have debt totalling more than half their household income (16 per cent, versus 8 per cent of households overall) and more than half (55 per cent) of disabled people report having no savings, compared to around 12 per cent of the general population (Gore and Parckar 2009). Disabled people find it harder to get credit, and are more likely to be refused insurance than non-disabled adults. One in 10 disabled people have used doorstep loans, compared to 3 per cent of the general population (Aiden and Bush 2013).

As well as this financial disadvantage, people with disabilities also face an increased cost of living. Brawn (2014) estimates this additional cost at £550 per month, directly attributable to a person's disability, and one in 10 spend more than £1,000 per month (Brawn 2014). This is highlights a particular and significant problem in cases where disabled people have lower levels of personal wealth.

> *'I can push a manual wheelchair with my right arm a little bit, indoors … but I can't go out on my own because I can't control it … I'm still not entitled to an electric wheelchair, even though I would have no quality of life without one.'*

In terms of property household wealth, Abigail McKnight (2014) found that the median level across all age-groups for disabled people was £108,000, compared with £138,000 for non-disabled people – an absolute gap of £30,000. However, in under-45 age-groups, median property household wealth is zero for disabled people.

Connectivity

Connectivity challenges affect both online access and access to appropriate transport. Despite the rise of new and assistive technologies and increasing opportunities for shopping and leisure over the internet, disabled people are significantly less likely to live in households with access to the internet than non-disabled people. According to a 2011 survey, 61 per cent of disabled people live in households with internet access, compared to 86 per cent of non-disabled people (Natcen 2011). In 2013, one-third of disabled people had never used the internet, and this group is four times more likely to have never used the internet as non-disabled people (ONS 2013c).

Where people do have access to the internet, there are social inclusion issues to consider as well, as one of our interviewees noted.

> *'I can use the internet to do my weekly shop but I choose not to because it's too easy to get stuck in the house and not interact with people in the community. There are social exclusion issues with using technology to make daily living easier.'*

In terms of transport needs, disabled people are less likely to have a car in the household: 60 per cent of disabled people have no car available to them, compared to 27 per cent of the overall population (DPTAC 2013). The transport select committee's inquiry into access to transport for disabled people (2013) found that more than a fifth of disabled adults experienced some difficulty when using public transport networks. Currently UK bus and coach fleets are not required to be compliant with accessibility regulations[3] until 2020. This means many bus routes now advertised as being operated with accessible buses sometimes run step access only buses, DPTAC (2013) found that this lack of reliability from the network means that many disabled people do not consider making a journey. A lack of on-board audio-visual information on buses also reduces the willingness of the visually impaired as well as the wider public to use buses (ibid).

Quality of life and social inclusion

In recent years, campaigns from Scope and Mencap have drawn attention to the poor quality of life indicators for people with disabilities. According to Mencap (2012), a quarter of adults with a learning disability report being stuck at home as a result of social care cuts. Furthermore, over 25 per cent of disabled people say they frequently do not have choice and control over their daily lives (ONS 2011).

Welfare reforms and public service cuts have resulted in a hardening of public attitudes towards people with disabilities. More than one-fifth of disabled people have experienced harassment in public because of their impairment (CPS 2007, citing DRC 2003). Almost half of respondents (46 per cent) interviewed by Scope (2013b) said people's attitudes towards them had gotten worse over the previous year.

These latest findings came against the backdrop of the 2012 London Paralympic Games, when it was assumed public attitudes might improve. In July 2013, the Department for Culture, Media and Sport completed an evaluation of the London Olympic and Paralympic Games in which it argued that the games 'improved attitudes to disability and provided new opportunities for disabled people to participate in society' (Thornton 2013).

Media coverage has fuelled myths about disability, with 73 per cent of people with disabilities encountering the assumption that they do not work and 83 per cent saying that coverage about 'benefits scroungers' negatively affects public attitudes (Scope 2012).

Poverty

Statistical evidence suggests that disabled people in the UK are twice as likely to live in poverty as non-disabled people (Gore and Parckar 2009). A more recent study by New Policy Institute found that poverty among disabled people is significantly underestimated, finding at least a 'missing million' of people in poverty in households with a disabled person (MacInnes et al 2014).

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[3] Public Service Vehicle Accessibility Regulations 2000.

A new report from the Independent Taskforce on Poverty and Disability finds that 19 per cent of people in families with at least one disabled member live in relative income poverty, before housing costs, compared to 15 per cent of individuals in other families. Moreover, 21 per cent of children living in families with at least one disabled member are in poverty, a significantly higher proportion than the 16 per cent of children in other families (Massie 2014).

There have been considerable reductions in financial support for disabled people and problems in the delivery of welfare assessments, including delays in personal independence payments and issues with the delivery of the work capability assessment (see for example Davies 2014a). These issues cause unnecessary distress and financial difficulty to disabled people. A survey of nearly 4,000 disabled people carried out by the Disability Benefits Consortium (2013) found that, of those hit by housing benefit changes like the so-called 'bedroom tax', more than one in 10 (12 per cent) have needed to use food banks to feed themselves and their families.

Accessibility

MacInnes et al (2009) highlighted a series of cases in which poor access to public services had a negative social and material impact on disabled people's quality of life. Almost 30 per cent of respondents had been unable to take up an education or training course because of inaccessible transport; around 18 per cent had been forced to turn down a job, and 48 per cent had missed a hospital appointment. Around a third of disabled people experienced difficulties related to their impairment in accessing public, commercial and leisure goods and services.

More than one-third of adults with a disability report experiencing difficulties accessing public services (ONS 2010). The five public services that disabled people most commonly have difficulty accessing are benefits and pensions, social services, health services, tax services and justice. Adults with disabilities report difficulties in accessing key services, namely shops, hospitals, leisure facilities and GP surgeries, where the most common barriers identified include moving around buildings (because of stairs, doors, narrow corridors and inadequate lifts or escalators) and the inaccessibility of toilets in public buildings (ibid).

These experiences were reinforced by participants in our discussion group.

> *'In London the buses are definitely better but there are still issues … the doors open in the middle so it's easy to get on but you need to scan your Oyster card and the scanner is at the front of the bus! If you're on your own you have to ask someone to scan it for you, so you are having to trust the people on the bus to pass your card up to the front, but it's got money on it … and it can be humiliating.'*

Housing

Disabled adults are more likely to live in homes that are inaccessible and in a state of substantial disrepair. One in five disabled people who require adaptations to their home believe that their accommodation is not suitable (ODI 2013). Disabled people are twice as likely as non-disabled people to be social housing tenants (ONS 2007) and there is a shortage of social housing that is specifically designed to meet disabled people's needs.[4] A lack of adapted housing means increased discharge delays: patients who need home adaptations, such as grab-rails or ramps, wait for an extra 27 days on average – more than 40,000 days in total – costing an estimated £11.2 million per year in delayed discharges (Age UK 2014).

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[4] Only around 1 million dwellings (5 per cent) possess all four of features that allow them to be considered fully 'visitable' for disabled people. Almost 6 million dwellings (26 per cent) had none of these four features (see DCLG 2014, Davies 2014b).

These issues were reflected by our focus group respondents, who felt that adaptations alone would not support them to maintain independence.

> *'Essentially I have just had to adapt to struggling through each day. Once I had a few grab-rails in place my house was deemed fit for me to live in. Personal care is a struggle, and it can take me a long time to get a load of dishes done because my sink isn't really accessible. I take frequent breaks but it's hard to go out to work each day and struggle with running a home on my own. I have had a few falls and my health is failing, but I'm not eligible for any support – you stop asking for help.'*

One in three households with a disabled person live in a home that fails to meet 'Decent Homes' standards.

There are four features which are considered to be the most important for enabling people with mobility problems either to access their home or to visit other homes:

- level access
- flush thresholds
- sufficiently wide doors
- bathroom facilities on the entry floor.

Only around 1 million dwellings (5 per cent) possessed all four of these features and could therefore be considered fully 'visitable'. Almost 6 million dwellings (26 per cent) had none of these four features (see DCLG 2014, Davies 2014b). Housing association homes were far more likely to have all four features than dwellings in other tenures, especially owner-occupied homes.

The younger people with disabilities that we interviewed reported that they fear they will not be able to find appropriate housing to enable them to live independent lives. Assistance with the cost of adaptations is available in the form of disabled facilities grants (DFGs) but this funding is limited and the integration of DFGs into the Better Care Fund means there is a risk that the positive emphasis on preventing future harm and expense may be lost.

Employment and economic activity

Although disabled people are more slightly likely to be in employment now than they were in 2002, there remains a persistent gap between the employment rates of disabled and non-disabled adults (as shown in figure 1.2). In 2012, 48.9 per cent of working-age disabled people were in employment, compared to 78.0 per cent of working-age non-disabled people – a difference of just over 29 percentage points.

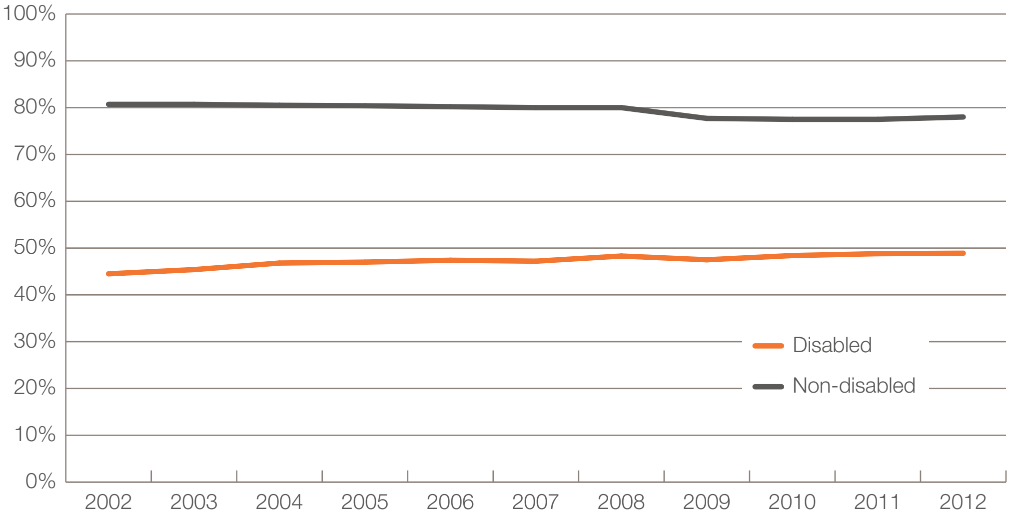
Breaking this down by disability type highlights huge differences in employment rates. For example, less than 7 per cent of adults with a learning disability (who are known to adult social services) are in paid employment (Mencap 2012).

Almost 46 per cent of working-age disabled people are economically inactive – that is, they are not actively seeking employment. This is two and a half times higher than the inactivity rate of non-disabled people, at just under 18 per cent (ONS 2012). Once disabled people become economically inactive they are less likely to move into employment: there were 3.7 million disabled people out of work in 2012, two-thirds of whom had not worked for five years or more (ibid).

Changes of policy and emphasis by the current Coalition government have had an impact on the number of disabled people in the labour market. Analysis by Scope (2014) of Department for Work and Pensions data shows that since 2008 as many as 654,000 disabled people who were not previously expected to find work are now required to do so – or 64 per cent of all those who have gone through the reassessment. Despite having been assessed as 'fit for work' through the work capability assessment (WCA), this group of people are likely to have complex support needs and may have been out of work for a long period of time. For many disabled people, decisions around 'fitness for work' are inaccurate and fail to account for the environmental barriers that disabled people face in trying to find work.

Figure 1.2

Employment rates for working-age adults, disabled versus non-disabled (Great Britain, 2002–2012)



Source: ODI 'Disability Equality Indicators' (ODI 2014)
Note: 'Working-age' adults includes males aged 16–64 and females aged 16–59.

Disabled people want to work (see figure 1.3) and government should make disability employment a priority. Beyond the social and economic benefits to the individual there is a wider societal benefit to disabled employment growth. In a report for the Disability Rights Commission in 2007, the Social Market Foundation calculated that improving the employment rate of disabled people to the national average would boost the UK economy by £13 billion (Evans 2007).[5]

Scope has highlighted the opportunities available through city deals for improving disability skills and employment support. Nearly 2.5 million disabled people live in areas already covered by city deals, more than 1 million of whom are out of work (Scope 2014). Government could incentivise job creation for people with disabilities within regional growth strategies.

Support for working-age disabled adults in work is vital to keeping a job. Many disabled people find that fluctuations in their health related to their disability prevent them from keeping to 'normal working hours', but that their workplace does not offer flexibility to help them stay in work.

> *'I was in work, I came off medication as I needed to go to a clinic to get it – given three and four days a week some weeks, I needed that medication – but I came off [that medication] so that I could get into work to work my hours. I decided to take the medication as an injection instead, but then my employer wouldn't let me do my injections in the work place … because of health and safety rules.'*

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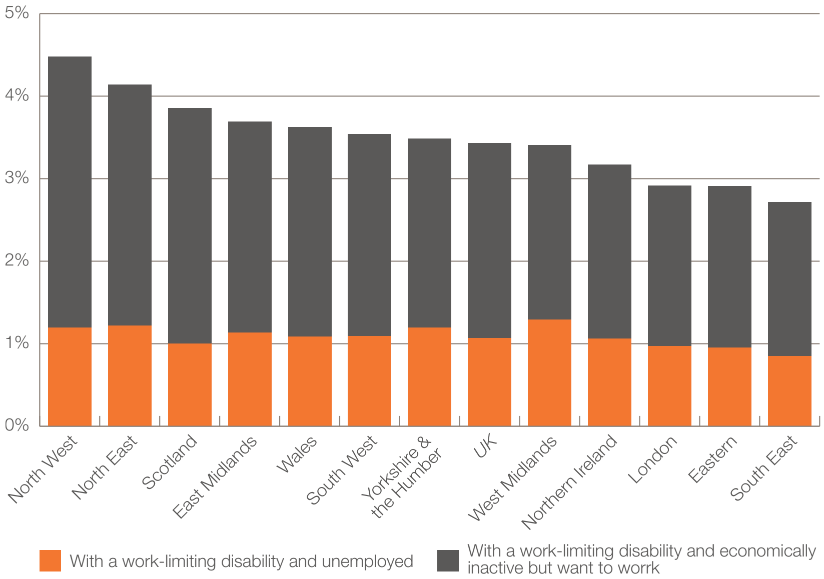
5 Using the methodology of the Leitch review, and taking costs into account.

Figure 1.3
Unemployment versus desire to work among working-age adults with a disability (UK, 2013)



Source: Author's analysis of ONS 'Labour Force Survey 2013, economic inactivity by reason, average of four quarters of 2013' (ONS 2013b)

Income

High levels of worklessness have meant that, throughout the last decade, around a third of all disabled adults between 25 and retirement age have been living in low-income households, twice the rate of non-disabled adults. The weekly income of disabled people who are solely dependent on benefits is approximately £200 less than the amount required for them to ensure an acceptable, equitable quality of life (Smith et al 2004).

No adjustment is made to disposable household income data to take into account any additional costs that may be incurred due to a disability. Currently, the ONS data release for 'households below average income' includes disability benefits such as disability living allowance and attendance allowance, as they make a contribution to the incomes of disabled adults. However, as described above, disabled people's costs of living are significant, and so their disposable incomes are likely to be significantly lower than the data suggests.

Education

Disabled people are around three times more likely than non-disabled people not to hold any qualifications (19.2 per cent versus 6.5 per cent respectively), and around half as likely to hold a degree-level qualification (Papworth Trust 2013). At the age of 18, disabled young people are more likely not to be 'not in education, employment or training' (NEET) as their non-disabled peers (22 per cent versus 15 per cent) and twice as likely to remain so for more than 12 months (ibid).

Looking ahead

In this chapter we have highlighted how people with disabilities face inequalities in all areas of daily life. As a result, they tend to fall through the gaps in services between health and social care – navigating the welfare system, housing and employment support services also impact on overall health and wellbeing.

Sir Michael Marmot’s recommendations on addressing health inequalities go further than reforms to health and social care systems alone:

> *‘[A]ction is required across all these social determinants of health and needs to involve all central and local government departments as well as the third and private sectors. Action taken by the Department of Health and the NHS alone will not reduce health inequalities.’*
> Marmot 2010

This report goes on to recommend that moves towards ‘whole person care’ should include consideration of the environmental barriers that people with disabilities encounter in accessing employment, public services and civic life, and to advocate for community-based support to navigate these complex pathways.

2.

A PARTIAL ACCOUNT OF WHOLE PERSON CARE: WHY SERVICE INTEGRATION BY ITSELF IS NOT ENOUGH

The shadow health secretary, Andy Burnham, has called for reform to England's health and care system to deliver whole person care. In her short report for IPPR, *Towards whole person care*, Sarah Bickerstaffe highlights two core elements to this vision. The first is making the connections between physical health, mental health and social care needs, and the second is supporting people to remain in their own homes as long as they wish (Bickerstaffe 2013).

Whole person care: a 10-year journey

'Whole person care' is an enabling approach and a relational approach – as opposed to being primarily transactional, where tasks are done 'for' or 'to' a patient.[6] Services are planned around the person to meet all their needs, across health, social care and mental health. Integrating services around the whole of an individual's needs, rather than following a separate medical and social model of support, enables them to be in control of their own conditions. Increasing choice and control, and 'seeing the whole person' is the foundation on which the disability independent living movement was built. The opportunity to integrate the systems and services people with disabilities use seems a natural progression.

While the aspirations of whole person care are the right ones, its case has generally been made around the needs of older people. This obscures the distinct needs of people of working age who are also accessing health and social care services. Indeed, there are risks to the independence of people with disabilities should the more intensively 'medical' model of the NHS come to dominate over a whole-person-care approach. This is because, first, medical outcomes vary widely from independent living outcomes and, second, the health inequalities facing disabled adults will not be resolved by integrating health and social care alone. Rather, as illustrated in the previous chapter, the wider determinants of health for working-age disabled adults lie outside of health and social care services.

Whole person care will only work, however, if services are able to deliver preventative care. Pressures on local authority budgets, combined with growing demand, mean that nine out of 10 councils in England only provide means-tested support for people with 'critical' or 'substantial' care needs (ADASS 2012). Removing social care funding at the moderate level for people with disabilities increases their vulnerability and reduces their independence. Aiden and Bush (2013) found that up to 105,000 disabled people are at risk of not receiving any basic support for their day-to-day activities as a direct result of the government's proposals for reform to social care eligibility criteria. There is a real risk that without preventative social care these people will need acute care in the short to medium term. Integrated services will not achieve better outcomes where people are not eligible for support with their basic but essential care needs.

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[6] For an introduction to a relational approach to public services, see Muir and Parker 2014.

Keeping people in their own homes for longer and reducing admissions for acute care requires preventative measures to keep people healthier for longer, meeting their needs in their home and community. However, this objective is complicated by the wide spread of the determinants of good health, beyond the narrow reach of health and care services. Whole person care must recognise that wider socioeconomic inequalities affect health outcomes – and this is especially apparent for people with disabilities who, as described already, face inequalities across most areas of daily living. As a response, this report argues for further integration across housing, employment, education and welfare, as well as health and social care.

A strong case has been made for improved integration of services by Richard Humphries (2011) and Ham et al (2012). However, without increasing resources upfront, real improvements in terms of cost efficiencies and service-user outcomes are unlikely to be unlocked through changes to delivery mechanisms alone. If the projected increase in the numbers of people living with multiple conditions is a challenge for the NHS in any attempt to ensure better service integration, then that challenge will also exist for social care services, where the people using their services are the same. In one local study, 90 per cent of people who received social care also received secondary health care over a three-year period[7] (CQC 2010).

This report recommends a long-term view is taken to long-term conditions: whole person care should be seen as a 10-year journey, and be supported with stable funding over this period.[8] While we recognise that it is challenging for the Treasury to commit funds over the long term, the crisis facing our health and social care system is not going to be fixed by integration in the absence of a long-term financial settlement. Indeed, the Barker commission found that higher public spending on health and social care is affordable if it is phased in over a decade (Barker 2014).

England's care crisis: it's not all about older people

The NHS faces a funding crisis: if real-term expenditure continues at current levels, an additional £30 billion per year would be needed by 2020/21 to fund the NHS. NHS England estimates that £22 billion may be saved by productivity gains, which leaves an annual shortfall of £8 billion (NHS 2014). At the same time, the social care system is in crisis, with fewer people receiving funded services to meet their needs: from 2009 to 2013, the number of older people receiving publicly funded social care fell by 26 per cent (Ishmail et al 2014).

Health and social care expenditure is currently skewed towards the management of long-term conditions. The 30 per cent of the population with one or more chronic conditions accounts for 70 per cent of all health and care spend (DoH 2012). There are 11.6 million disabled people in Britain, of whom almost half (5.7 million) are working-age adults (aged 18–64) (ODI 2013). As of 2012, about 15 million people in England had a long-term condition for which there is currently no cure; in these cases, conditions are managed with drugs and other treatments. This group now accounts for around half of all GP appointments, 64 per cent of all outpatient appointments and over 70 per cent of all inpatient bed-days (DoH 2012).

In 2012/13, social care for working-age people with learning disabilities accounted for 30 per cent of gross current expenditure on social care, or £5.2 billion; those with physical disabilities accounted for 9 per cent (£1.6 billion), and those with mental health needs for 7 per cent (£1.1 billion) (see figure 2.1). Slightly more than

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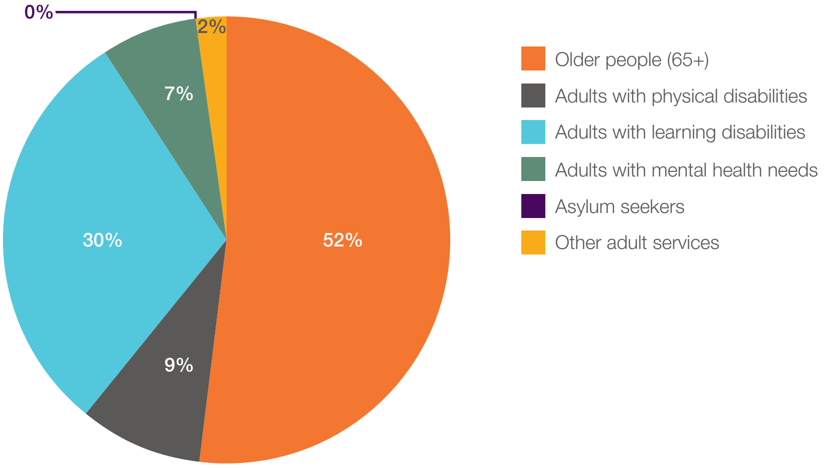
[7] Secondary care refers to the care a patient receives in hospital, as either an in-patient or an out-patient. This may highlight that people do not always fall into separate categories of 'health' and 'care' needs and so these needs may be met more effectively where the NHS and social care provide an integrated service.

[8] Previously, the House of Lords has also called for a 10-year funding plan for health and social care (see HLSC 2013).

half of all NHS expenditure in England is spent on the under-65s, and roughly half of social care expenditure is spent on working-age adults (Barker 2014).

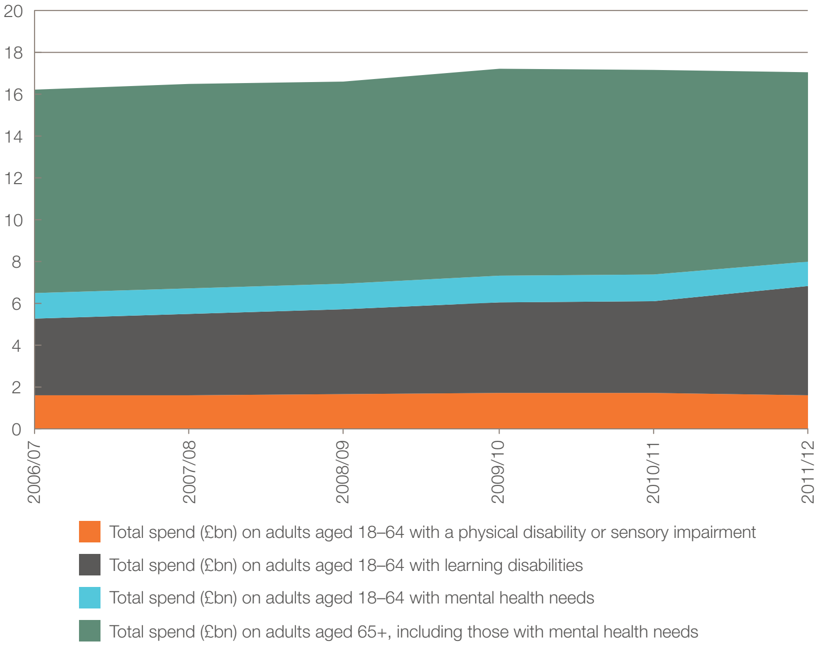
Figure 2.1
Breakdown of social care spending (share of gross current expenditure in real terms, by client type, England, 2012/13)



Source: HSCIC 2013

Half of the adult social care budget is spent on care for older people. However, there has been a trend of reduced spending related to older people's and physical disability and sensory impairment services, while spending related to learning disabilities and mental health has risen (see figure 2.2).

Figure 2.2
Trends in historical social care spending (England, 2006/07–2011/12)



Source: Audit Commission 2013

As the Barker commission has highlighted, the crisis deepens when we look at projected levels of future demand (Barker 2014). Projections suggest that the numbers of older people needing care will continue to grow significantly – the number of people aged over 80 is expected to double to 6 million by 2037 (ibid). The commission has recommended that the government should plan on the assumption that public spending on health and social care will reach 11–12 per cent of GDP by 2025 (from the current level of 9.7 per cent of GDP), and proposes a new settlement for health and social care funding that is based around the principles of whole person care and includes changes, for example, to national insurance contributions, to provide the additional £5 billion that would be required to broaden and sustain social care entitlement.

Given the drive to meet the increasing demands of an ageing population, it is perhaps inevitable that the whole person or integrated care agenda has tended to explore how the system needs to be reformed to support the needs of older people. We support these recommendations to make better connections between physical health, mental health and social care needs, and support people to remain in their own homes as long as they wish. However, crucially, we recommend that service reforms must also take account of the distinct needs of other groups in society, that is, including working-age disabled adults, people with mental illness and people with long-term conditions.

Not only have medical advances done much to keep older people healthier for longer, they have also benefitted many younger people with disabilities, people who in times past might not have survived their early years.

Barnett et al (2012) studied the records of more than 1.75 million patients in Scotland, and found that in absolute numbers there were more people with two or more conditions in the under-65 age-group than there were among those aged 65 or more (210,000 versus 195,000 respectively). In addition, many of these younger people had a mix of physical and mental ill health needs, which in concert demand a better-aligned health and social care system. There have been many studies exploring and evaluating integrated care for older people, but data is still scarce concerning integrated care outcomes for working-age disabled adults who also use significant health and social care resources.

In the course of research for this report, we found few case studies or examples of integrated care schemes that tested whether there were improved outcomes for people with disabilities and long-term conditions. Generally, studies have focussed on older people, where there is strong evidence of positive outcomes. In the next chapter, we draw out lessons from our discussions with working-age disabled adults about how 'whole person care' could provide better outcomes for them in their lives.

3.
INTEGRATED CARE OUTCOMES

The purpose of whole person care is to coordinate services around an individual, with a stronger emphasis on care provided outside of acute settings. Its objective is twofold: to drive efficiency and to be preventative.

On the first objective, it is generally presumed that integrating health and social care systems delivers better value for money. However, cost-saving benefits are as yet unproven, and this is an area that remains under-researched. It should not be assumed that integration will necessarily bring about efficiencies (see Bickerstaffe 2013).

Evidence is generally stronger on the second objective, in terms of the effectiveness of integrated care for the patient (although there is much less evidence and data on integrated care outcomes for working-age disabled adults, as previous studies have tended to focus on older people). Where integrated health and social care services increase the effectiveness of care by helping to maintain connections between service users and their communities, it is likely that people will be able to remain in their own homes for longer – that is, outside of acute care settings.

Currently, however, where services are not responsive to the needs of the individual, services break down and people end up using expensive hospital care instead. This represents a failure to provide basic preventative care earlier.

This chapter presents a summary of previous research into the potential outcomes of service integration for users, in terms of their experiences of integrated services, and their preferences and priorities. It is also informed and illustrated by the discussion groups run by IPPR North as part of this research.

Key outcomes of service integration for service users

Hiding the wiring

Four of our focus group respondents highlighted a lack of funding for supportive services to help them to manage their own conditions. Hydrotherapy, for example, was one service where people felt funding should be increased. This highlights a need for 'hiding the wiring', to insulate users from having to secure funding for their own services, which has happened in some cases.

> *'In the past I have found hydrotherapy and physiotherapy helpful for pain management, but I have hit a wall. Health will say this is a social care need, social care say it's a health need … The GP said "if you can find someone to fund it we can arrange it for you".'*

> *'I've been told in no uncertain terms there is equipment that I need and the hospital is writing to charities to get funding for it, as I can't afford to pay for it myself. I saw my GP, who told me that the hospital should pay. I'm caught in an argument between the two – it should be about what's best for me, not how much it costs or who pays.'*

> *'I have physiotherapy in Newcastle and see a consultant there, and they both had said that I needed to get new equipment. But because I live in Northumberland and go to a hospital there, I said to [the hospital] that my consultant said I needed new splints and they said "you don't really need them". I feel it's so contradictory to what my consultant said. They say it's about budgets.'*

> *‘I was prescribed medication for my condition and I tried a few different chemists and none of them could get it because of a supplier problem, the chemist suggested an alternative medication and suggested I try to get a prescription for that but the doctor wouldn’t prescribe it and told me to try more chemists further afield so I had to pay for travel out of the area just to sort out my prescription.’*

Telling your story once

National Voices (2013) found that people wanted to be able to tell their story only once in the process of accessing different health and care services. Working-age disabled adults want to live independent lives, and told us that they want their health and social care concerns to form just a small part of their interactions with public services.

> *‘I changed GP surgeries recently because I was getting appointments with locums and never getting to see the same GP twice. I had no continuation … I have to start right from the beginning, taking up most of the appointment with talking about my history, what was wrong with me, going way back … That’s been a real hindrance.’*

> *‘I don’t want to spend the best part of my lunch break chasing up doctors and my social worker and explaining my back-catalogue of health and care needs, arranging to change support workers or asking them to come at a different time … I want to enjoy my lunch break like everyone else does, not do my personal health admin every day!’*

Becoming an expert in your own care

A relational and enabling approach to care and support enables people to manage their own conditions where possible, either on their own or with others. The ‘Expert Patient’ programme within the NHS puts the person at the centre of their own care, by building and valuing their expertise in understanding their own condition.

> *‘You have got to take responsibility for your condition as well, I have got to ask questions and can’t just accept the information. I have to question it – this condition affects different people in different ways … you have to know the right questions to ask and I have learned what they are over the years … through talking to other people who have this condition too.’*

Most working-age disabled people that we spoke to sought some form of peer support to help them manage their disability.

> *‘I speak to people who have the same condition as me, generally they know more about the latest treatments and trends in managing this condition.’*

> *‘I use online forums and Facebook pages for people with my condition. It’s opened up a community for me, and I really value the friendship and support. I found out about the support agency I use through these groups – having a trusted recommendation was important, and my social worker couldn’t give me that.’*

Having a single point of contact

The people we spoke to were dissatisfied with their interactions with social care services in particular.

> *‘In this area you don’t get a social worker. You are looked after by a social care ‘team’, but they don’t know who we are, they don’t know anything about my son and … no one person is responsible.’*

A single point of contact is very important to these people. There was some disagreement about who should fulfil this role: on the whole, the voluntary sector is valued for providing 'better coordination because they know the community better'. Issues were raised about potential problems with information-sharing, but there was widespread recognition among our focus group participants that better coordination is necessary to ensure people are not allowed to fall through the gaps.

> *'My GP would tell me to contact my social worker. My social worker wanted to organise a meeting with lots of other professionals to talk about my care package – and I felt stuck in the middle. I called my social worker, and then I got a letter through the post that my wife and I couldn't really understand. I just wanted someone to talk me through the process.'*

Avoiding system clash

Problems occur where people are caught in the middle of the health, social care and welfare systems. Delays to assessments for welfare benefits, for example, impact on people's ability to meet their day-to-day costs. Aside from the pressure this places on people – pushing them to use food banks and short-term loans (see Trussell Trust 2013) – there are health impacts too.

> *'My mental health really suffered while I went through the assessment period. There was this constant round of telephone calls and chasing up … Financially I was worried: using the gym and warm water really help me with my mobility, but I couldn't get any financial support so those things had to stop. My physical health started to suffer and I became really quite frail during that time.'*

Achieving appropriate outcomes

Fiona Aspinal (2012) has identified a set of outcomes for people with long-term neurological conditions (LTNCs), recognising that the demographic profile of this group is generally younger. She found that many of the outcomes that are important to service users with LTNCs are not covered by the set of validated health and social care outcome measures.

The way that teams interpret and assess outcomes reflects their priorities and their approach to practice. Aspinal found that neuro-rehabilitation teams that focused on functioning and medication issues interpreted and assessed the outcomes in more limited ways than other practitioners. In teams with a more interdisciplinary and holistic approach, professional boundaries were more blurred and practitioners were willing to explore more holistic outcomes with patients outside their immediate expertise (ibid). These 'other outcomes' were generally measures of wellbeing, and for people with LTNCs included levels of household cleanliness, financial security, personal decision-making, access to all areas of the home, access to other places and facilities, contributing to the wider community, and developing and maintaining family and wider relationships.

> *'I would love to have my own home, and to get a job. These are my personal goals. But they're not the questions that anyone asks me in assessments – it's all about what self-care I can manage, it's all short-term, day-to-day stuff.'*

The lesson here is that outcomes need to be viewed holistically. Individuals should receive support to define and realise the outcomes that matter to them.

Broadening personal budgets

The personal budgets agenda has been more successful for disabled adults using social care than for older people. The Barker commission recommends including attendance allowance in a new single ringfenced budget for health and social care for older people (Barker 2014). Barker acknowledges that a similar single budget could be extended to working-age disabled adults, but that the transition to personal independence payments (PIP, which helps with some of the extra costs caused by long-term ill-health or a disability for people aged 16 to 64) must be concluded before these steps are taken.

The ‘Right to Control’ pilot (2010–13) has shown that having control over money is not the same thing as having control over care. The pilot scheme was designed to enable disabled people to pool resources from up to six funding streams – adult social care, Supporting People, Independent Living Fund, Disabled Facilities Grant, Work Choice and Access to Work – and exercise choice and control over how their combined personal budget was spent. However, many participants did not feel this pilot gave them more choice and control; indeed, there was evidence that personal budgets were as restrictive as traditional forms of service delivery, as a meaningful choice of services was not available for budget holders to select between (Tu et al 2013).

An evaluation of the scheme found that personal budgets were most effective when staff explicitly told disabled people that they could make changes to their support, when they received meaningful options and could make an informed choice, and when disabled people received help in arranging their support (ibid).

Ensuring employment support works

Employment support services play a vital role in ensuring that as many disabled people as possible are able to work. Integration between employment support and social care services would identify and address cases where a lack of social care support is preventing working-age disabled adults from finding employment.

As outlined in the previous chapter, data shows that well over half a million additional disabled people are now expected to find work. This group are likely to have complex support needs and face environmental barriers to work, and may have been out of work for a long time (for further discussion, including on work programme outcomes, see Davies 2014a). IPPR made a series of recommendations to address these issues in the final report of its *Condition of Britain* programme, based on the principles of increased social investment, clear obligations on people who are out of work, and promoting ‘contribution’ through paid work among as many citizens as possible (Lawton et al 2014). To summarise, those recommendations include a more focused Work Programme; a separate, qualitatively different ‘New Start’ programme for people with long-term health conditions or disabilities; a job guarantee to prevent long-term unemployment; and steps to increase the retention of sick and disabled people in the workplace and to improve the incentives for employers to hire them in the first place.

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In supporting working-age disabled adults to live more independent lives, integration of services is not an end in itself. The ‘whole person care’ approach would be considered successful only when it delivers most, if not all, of the types of outcome and improvement outlined in this chapter, and does so across the full range of social policy areas, not just health and social care alone.

4.

DELIVERING INTEGRATION THAT MEETS THE NEEDS OF ADULTS WITH DISABILITIES

Having defined the problem and highlighted some of the key outcomes for working-age disabled adults, this chapter looks at specific recommendations for achieving fundamental reform of services.

Engagement and enabling that works for everyone

The landscape of health and social care has been transformed in recent years. The Health and Social Care Act 2012 transferred a range of health functions to the local level (from 2013). Local authorities now have a much greater responsibility for improving their citizens' wellbeing, having taken on the public health roles of the abolished primary care trusts. The majority of the NHS budget (£65 billion of the £95 billion NHS commissioning budget) in England is overseen by 221 clinical commissioning groups (CCGs), and local authorities are responsible for the implementation of coherent strategies at the local level through their leadership of 130 new health and wellbeing boards.

The £3.8 billion Better Care Fund (BCF; formally the Integration Transformation Fund) was announced by the government in June 2013 to underpin a transformation in integrated health and social care. The fund creates a local, single pooled budget to incentivise the NHS and local authorities to work more closely together around people, with their wellbeing as the focus of health and care services.

There are five national metrics for monitoring BCF performance:

- admissions to residential and care homes
- effectiveness of reablement
- delayed transfers of care
- avoidable emergency admissions
- patient/service user experience.

On the local level, health and wellbeing boards are responsible for managing BCF plans and expenditure, and each chooses an additional metric for measuring progress towards integration. Analysis by the *Health Services Journal* of 60 draft BCF submissions has found that many areas had picked very similar metrics as a proxy for service integration, the most popular of which centre around dementia diagnosis, falls and carer support (HSJ 2014). Although many include the proportion of people feeling supported to manage their (long-term) conditions as a key measure, it is clear that BCF plans, in the main, are focussed around older people.

Health and wellbeing boards should look to their joint strategic needs assessments (JSNAs) and check that integration plans meet the needs of all service-user groups, including working-age disabled adults. Without doing so, there is a danger that remodelling or integration of services takes place in a way which meets the needs of older people but not the wider population of health and social care users. NHS England recognises that there is no single, national measure of patient satisfaction suitable for measuring progress towards integration, and are developing a national measure of patient satisfaction for 2015/16. We recommend that this measure is co-produced with patients, service users and carers, and includes relational outcomes (that is, outcomes which measure the connections individuals have with their community and how these are maintained) and quality of life measures.

The Kings Fund's review of the first year of health and wellbeing boards found that few identified public engagement as a priority. Yet, when asked which three factors (local or national) would most help boards to achieve their priorities, strong working relationships, effective partnerships and stakeholder engagement were considered by far the most important (Humphries and Galea 2013). Health and wellbeing boards have a duty to involve the local community in undertaking their joint strategic needs assessment and to include data on the impacts of the wider determinants of health in the local area. Understanding the distinct needs of different service-user groups will be critical to the success of integrated services, and so boards should seek to understand what good outcomes and 'customer satisfaction' would look like for vulnerable groups. A NAVCA study (2013) found examples of good practice in JSNA planning, such as the Voluntary Sector Engagement Project.

Health and wellbeing boards should lead local authorities and clinical commissioning groups to build a clear understanding the distinct needs of different service-user groups in the local area and seek to strengthen local community organisation networks, with a view to supporting people to stay in their own homes for longer.

Case study: joint commissioning in Stockton-On-Tees

The rising number of people with long-term conditions suggests a growing need for promoting and supporting self-management. The effects of behavioural changes, such as obesity, are becoming increasingly difficult to manage, and emergency admissions continue to increase, many of which would often be avoidable with the benefit of effective social and welfare support.

Generally, investment in voluntary and community sector (VCS) services and projects is expected to enhance developments in community services and enable better delivery of care closer to home. The Hartlepool and Stockton clinical commissioning group recognises that the VCS is a key partner and resource.

The clinical commissioning group has identified specific aims and objectives for the coming year:

- Stockton council's public health team is a key partner in the delivery of the *Joint Health and Wellbeing Strategy 2012–2018*, and aims to commission a range of initiatives that promote and deliver early intervention, health promotion and self-management, resulting in a healthier, better informed community.
- This is a joint commissioning project between the clinical commissioning group and public health team. The steering group is made up of representatives of both, and of Catalyst Stockton, the local representative VCS body. The scale of the joint commission is as follows:
  - £300,000 from Stockton council public health
  - £333,000 from Hartlepool and Stockton clinical commissioning group
  - managed by Catalyst to facilitate a VCS response to the challenge of improving health outcomes.
- Working as a partnership, Catalyst Stockton, the clinical commissioning group and public health team are inviting the VCS in the borough to innovate, collaborate and develop projects that will meet a range of the outcomes identified to be met by the grant funding.

Source: Catalyst 2014

Strategies like 'Valuing People Now' and 'Putting People First' engaged well with service users and carers, and there were strong examples of good practice in user involvement and engagement. However, once funding for these strategies came to an end in 2012, the self-advocacy networks and involvement groups themselves had no resources with which to continue their work.

At a time when people with disabilities are misrepresented in the media and face multiple forms of inequality in daily life, the voice and campaigning of service users is crucial. Without it, there is a danger that public attitudes towards people with disabilities continue to harden.

Conversely, an enabling approach to disability care would be strengthened by user groups that feel empowered. We recommend that investment is made into local 'Fulfilling Potential Forums', self-advocacy groups developed by disabled people's user-led organisations (DPULOs) to engage with health and wellbeing boards and amplify user voices in local policy development. In April 2014, a 'national' Fulfilling Potential Forum was set up by the Department for Work and Pensions in collaboration with the Department of Health to ensure the needs of disabled people are considered by government policymakers. This should be replicated at the local level.

The Office of Disability Issues (ODI) invested £3 million in 2013/14 to strengthen DPULOs. This funding provides capacity-building support to over 170 DPULOs, and funded the set-up of new DPULOs, but did not have a strong impact in terms of user voice. We recommend that an additional £3 million should be invested in local Fulfilling Potential Forums to build on this;[9] these funds should be distributed by local health and wellbeing boards to support the development of DPULO self-advocacy groups to engage with the boards' work and to amplify user voices within local policy development. This funding would equate to about £20,000 per board area.

This need not stop at health and social care policy – self-advocacy groups should engage with local policymaking. As noted in chapter 1, nearly 2.5 million disabled people live in areas covered by city deals, with more than 1 million out of work. We envisage that this additional investment in DPULOs could enable people with disabilities to make representations in other local policy areas, including city deals.

Funding that recognises the distinct needs of disabled adults

The Barker commission made some recommendations focussed on the distinct needs of working-age adults, for example, around funding moderate care needs (Barker 2014).

Although needs are 'moderate', their impacts can be significant. 'Moderate needs' means:

- there is, or will be, an inability to carry out several personal care or domestic routines
- involvement in several aspects of work, education or learning cannot or will not be sustained
- several social support systems and relationships cannot or will not be sustained, or
- several family and other social roles and responsibilities cannot or will not be undertaken (DoH 2010).

Scope (2013a) has estimated that social care for working-age disabled adults is underfunded by £800 million (citing Fernandez et al 2013). If social care funding were extended to working-age disabled adults with moderate needs, it is estimated that every pound spent would result in savings of £1.30 to the public purse. The population that is reliant on the social care system to support them in their everyday lives is projected to rise from 1.1 million in 2010 to 1.3 million in 2020 (LSE 2010).

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[9] Local Government Association has called for an extended Better Care Fund offer to 2020 including a transformation fund to support integrated care outcomes (LGA 2014). We recommend that £3 million of this funding is allocated to supporting DPULOs to amplify user voices in the work of health and wellbeing boards.

The reality of moderate-level needs is that some people cannot get out of the house without support with personal care or domestic routines. They may be reliant on friends and family, which can place a strain on relationships, particularly where carers are ageing. As they need more support to get out and about, people tend to withdraw from social and educational opportunities, increasing social isolation and loneliness.[10]

The Barker commission calls for a system in which all patients with 'critical' needs would receive free social care, with an ambition to extend this to those with 'substantial' and 'moderate' needs (Barker 2014). Of course, there is a debate to be had in the long term about how health and social care is funded. However, we recommend that any assessment of funding should take account of these distinct needs, particularly as Barker suggests changes for working-age adults will need to be phased in over time, where the transition from disability living allowance to personal independence payments is still ongoing.

Care that meets the needs of disabled adults

Our current system places a strong emphasis on acute and episodic care, but people with disabilities and long-term conditions do not use care services in this way. They use more services over longer periods of time; for this group of patients, integrated care could bring positive outcomes, by prioritising prevention and improving service quality and the user's experience.

A study of NHS examples of coordinated care for people with long-term conditions showed positive outcomes, including empowerment of patients and carers, improved quality of life, and high staff satisfaction (Goodwin et al 2013). There is evidence that care which is more coordinated can facilitate earlier intervention, thereby reducing later demand for GP consultations, outpatient visits and emergency admissions. People with chronic health conditions do not want to be admitted to hospital unless it is absolutely necessary (DoH 2012); if they can access services and support where they live then they are less likely to have to be admitted.

The picture at the moment is very mixed, however.

- The national evaluation of the NHS Evercare programme found that patients and carers were very satisfied with the service they received, but there was no overall effect on emergency hospital admissions (Boaden et al 2006).
- Evaluation of the Expert Patients programme found improvements in self-efficacy and quality of life, and high levels of patient satisfaction with the programme. There were some reductions in the cost of hospital use (inpatient stays and day cases) but no impact on routine health usage (GPs, practice nurses and outpatient visits) (Rogers et al 2006).
- Evaluation of the Partnerships for Older People projects reported staff as saying that changes had improved services for older people in terms of their quality of life and wellbeing. It was difficult to assess the impact on older people, and the range of measures the evaluation used produced mixed results across the sites. Overall, it found that overnight hospital stays were reduced by 47 per cent and A&E use was reduced by 29 per cent (Windle et al 2010). However, later analysis by the Nuffield Trust using matched controls found no reduction in emergency admissions (Bardsley et al 2013).
- Evaluation of the Integrated Care pilots found that staff reported improvements in care, most of which were process-related, but that patients did not appear to share the sense of improvement. There was some evidence of reductions in inpatient and outpatient costs but no reduction in emergency admissions (RAND Europe 2012).

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[10] For further IPPR work on social isolation, ageing and caring, see Clifton 2011 and McNeil and Hunter 2014.

- The Nuffield Trust's evaluation of the first year of the north-west London Integrated Care pilot found that health professionals believed the pilot had improved collaboration across the system. There was no significant reduction in emergency admissions (Bardsley et al 2013).

Nevertheless, large variations across the country in the rate of emergency hospital admissions for conditions which could be managed out of hospital suggests that there is potential for improvement (Bickerstaffe 2013). Recent work by the Health Foundation and the Nuffield Trust suggests that 20 per cent of emergency admissions are potentially avoidable, and that there is considerable variation between areas, not all of which is the result of relative deprivation (Blunt 2013) – that is to say, it is possible to do a better job of reducing the incidence of acute care. Given that the 30 per cent of the population with one or more chronic condition accounts for 70 per cent of all health and care spend (DoH 2012), any reductions in hospital use (the most expensive type of care) will produce economic benefits.

The National Audit Office reports that many emergency admissions are avoidable, and that many people stay in hospital longer than is necessary (NAO 2013). It suggests that one way to reduce these admissions is for primary, community and social care to manage long-term conditions more effectively. Although evidence of cost-savings from doing so is less well developed and admissions reductions are not always found, there are examples of integrated services reducing acute admissions and impacting positively on transfers (see the Torbay case study below). Although existing findings are generally limited by their focus on older people, we spoke to many people of working age with disabilities who live alone and feel that they would benefit from this kind of reablement support on leaving hospital or other acute care facilities.

Case study: reablement in Torbay

In Torbay, five integrated health and social care teams, work alongside GPs to provide a range of intermediate care services, supported by health and social care coordinators (Thistlethwaite 2011). They use pooled budgets, and serve areas of around 30,000 people.

By providing support around discharge from hospital, they have helped older people to live independently in the community, as seen in a reduction in emergency bed-use by older people, the elimination of delays in transfers between services, and high levels of patient satisfaction (Goodwin et al 2012). Care coordinators support older people following an emergency admission to hospital, helping them to access the intensive support required to enable them to live at home following their discharge. Efforts to improve this reablement process have tended to be built around community-based multidisciplinary teams, often including the specific role of care coordinator. Interestingly, care coordinators have no professional background, which highlights the possibility of developing new roles within integrated health and social care. 'Coordinators do not have formal professional training but know how to harness the contribution of team members to improve the care of "Mrs Smith" and people like her' (Thistlethwaite 2011).

Case study: care planning in Wigan

In Wigan, integrated care planning recognises the distinct needs of working-age adults with disabilities, working to develop care plans and services around the individual. For adults of working age, Wigan Borough Council is developing 'risk stratification tools' that predict the usage of a range of public service interventions, without which some residents and patients can 'bounce' between a range of different services (primary care, benefits payments, criminal justice, A&E, adult social care) without improving their situation and at a cost to the system.

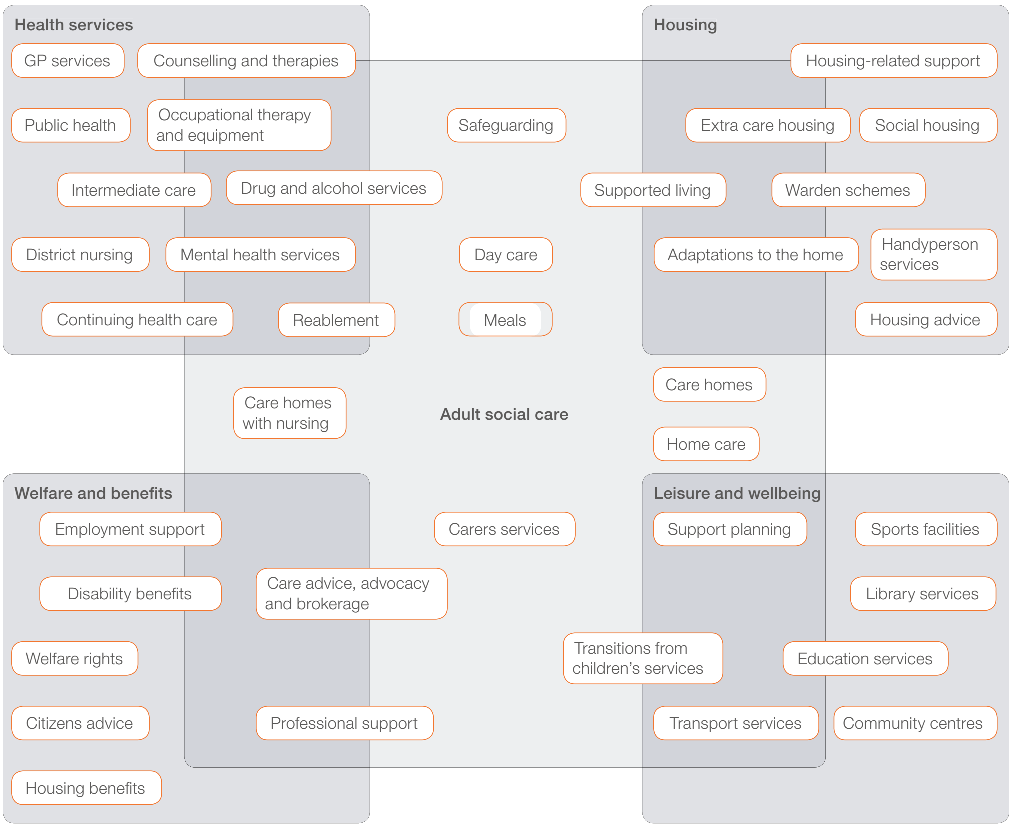
This alignment of a range of planned and preventative interventions to a 'risk stratified' cohort of adults of working age is a crucial element of a wider programme of public service reform in the area. There is a commitment to strengthening and developing Integrated Neighbourhood Team Programmes, which utilise risk stratification to identify individuals at risk of hospital admission. The programme ensures that a care plan is developed with the individual and a team of health and care workers, led by the individual's GP, to create a care plan coordinated by a single professional (WBC 2014).

Coordinating care and support around the individual

As chapter 1 illustrated, the range of inequalities impacting on the lives of people with disabilities will not reduce without integration with other public service areas beyond health and social care alone. The crucial role of housing, employment, education and other local facilities in health and wellbeing calls for networks that allow wider collaboration, beyond more integrated organisations.

Mapping out the interactions that disabled people have with public services highlights the need for a single point of contact in health and social care but also across other public services, in order to keep people healthier for longer. This is particularly the case for people of working age, for whom managing many complex interactions can impact on their ability to take up employment.

Figure 4.1
How adult care services overlap with other public services



Source: Reproduced from NAO 2014

A system for the delivery of whole person care needs to understand the complexity of people's interactions with services. As noted in the previous chapter, a key frustration for adults with long-term conditions is the sheer number of assessments they undergo in most areas of public life, and that they have to tell their story repeatedly to an ever-increasing range of public service professionals (National Voices 2013). For integrated care to best meet the needs of people with disabilities, service integration should take place across a much wider base of services, supported by care coordinators rooted in communities (as in the Torbay case study above).

Case study: coordinating housing support

Amanda, 39, has a learning disability and chronic obstructive pulmonary disease (a respiratory disease). She is living in a private tenancy property. The stairs are difficult for her to manage, and there is mould growing in the property which could be aggravating her condition. Amanda is on the housing list with her local authority, but was looking at inappropriate properties. She did not understand the process, and the local authority did not know the details of her condition. With the support of an advocate, Jill, who worked with Amanda to identify her needs, together they have clarified the issues for the housing team. Her advocate has also been able to monitor Amanda's place on the waiting list for a tenancy support worker. A worker has recently been allocated to support Amanda with debt and finance issues, and to coordinate the moving process more efficiently. Jill will keep working with Amanda until she is rehoused in a suitable property.

It is also apparent that effective management of long-term conditions requires not just coordination between different levels of care but also to harness an individual's own capacity for self-help and self-management (Hibbard and Greene 2013).

Case study: Sandwell Esteem

The Sandwell Esteem Team is part of the Sandwell Integrated Primary Care Mental Health and Wellbeing Service (the Sandwell Wellbeing Hub) in the West Midlands. The hub takes a holistic primary and community care-based approach to improving social, mental and physical health and wellbeing in the borough of Sandwell.

The team employs six link workers who provide care coordination for complex patients. The link workers act as patients' navigators through the health and social care system. Typically, they have a social worker background or personal experience with mental health conditions. The Esteem Team can refer patients to a wide variety of statutory and voluntary sector services, including social services, debt advice agencies, substance abuse counselling, therapeutic services and peer support groups.

The patient is never left unsupported: if a therapy or care intervention is not successful they are encouraged to try a different hub service. The care coordinator makes a referral to the new service, so patients cannot get 'lost' in the system. This differs from standard practice, where a patient can access a certain number of therapy sessions but then has to seek out a new referral from their GP once these end.

Link workers form close relationships with their patients, building their confidence and self-esteem. They will visit patients at home and accompany them to appointments if required. The Esteem Team's work is not time-limited: patients will be discharged from the service only if the link worker and the clinical coordinator agree on discharge, using guidelines developed by the service.

Source: Thiel et al 2013

It is clear from this example that there are good outcomes for patients and the rate of mental health admissions looks to be falling (although the project's own evaluation was cautious about these findings, due to small sample sizes).

This care coordinator role could work well for adults with disabilities. In shifting resources from community care case management to community coordinated care, we recommend that disabled people should have a single point of contact for all health and social care needs, and that this contact should have responsibility for making sense of complex service pathways, 'hiding the wiring' from the service user and identifying peer support options. There are clear areas where this would save money: for example, given appropriate resources and powers to secure a place on leaving acute care, this would reduce delayed transfers. For adults with learning disabilities, in cases of acute admissions for 'ambulatory care sensitive conditions' – conditions which, when managed at the primary care level, should not normally result in a hospital admission – the care coordinator's role would be to increase continuity of care with the patient's GP.

Case study: care coordinators and people with learning disabilities

Recent work by the Health Foundation and the Nuffield Trust (Blunt 2013) suggests that 20 per cent of all emergency admissions are potentially avoidable. Data relating to ambulatory care sensitive conditions (ACSCs)[11] highlights trends across disability types. Glover and Evison (2013) found that when people in their learning disabilities study group were admitted to hospital, compared to other people, it was 25 per cent more likely to be as an emergency, and 70 per cent more likely to be as an emergency for an ACSC. This suggests that primary care for this group was not as effective as it was for others. Unlike people without learning disabilities, for this group, emergency admissions for ACSCs occurred across the adult age spectrum: they were not predominantly confined to older ages. While in most respects the profile of clinical conditions involved was similar at similar ages, one condition – convulsions and epilepsy – stood out as by far the most frequent cause for people in our learning disabilities group. This one cause accounted for more than 40 per cent of all emergency admissions for ACSCs for people with learning disabilities – 6,000 admissions and 28,000 bed days per year. On an average day there will be 75 people with learning disabilities in hospital in England for this reason.

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[11] Conditions which, when managed at the primary care level, should not normally result in a hospital admission.

5.
RECOMMENDATIONS

The drive towards whole person care is the right one. In this final chapter, we put forward a series of recommendations to ensure that the distinct needs of working-age disabled adults are met, and that the health inequalities they face are taken into account in the process of remodelling integrated health and social care services. This is to counter the risk that a narrow focus on the needs of older people alone could mask the specific needs of other groups of health and care service users.

- Recommendation 1: **A long-term view should be taken to managing long-term conditions, and so we recommend that whole person care should be conceived as a 10-year journey, matched by stable funding over this period.** While we recognise that it is not easy for the Treasury to commit funds over the long term, the crisis facing our health and social care system is not going to be fixed by integration in the absence of a long-term financial settlement.

- Recommendation 2: **The continuing debate about how to manage the funding gap in social care must take into consideration the needs of working-age disabled adults.** In particular, the funding gap in addressing moderate care needs disadvantages working-age disabled adults, who already face structural challenges, including disparities in employment rates and the cost of living.

- Recommendation 3: **Prevention must remain high on the agenda when planning services over the long term.** High-quality care would focus on enabling individuals to manage their own condition in order to slow down its progression or prevent their problems worsening and requiring hospital or residential care.

- Recommendation 4: Supporting prevention would be strengthened by shifting resources from case management to community coordinated care. **Disabled people should have a single point of contact for all health and social care needs.** This contact should have responsibility for making sense of complex pathways between services, 'hiding the wiring' from the user, and identifying peer support options to help people understand and manage their conditions.

- Recommendation 5: A key frustration for adults with long-term conditions is the sheer number of assessments they must undergo and how often they have to retell their story to public service professionals who are unfamiliar with their circumstances. **For integrated care to best meet the needs of people with disabilities, service integration should take place across a much wider range of services, beyond health and social care**, supported by care coordinators rooted in communities.

- Recommendation 6: **Health and wellbeing boards should lead local authorities and clinical commissioning groups in prioritising public engagement across all service user groups.** This is to ensure that progress towards integrated care can be measured according to the demographics of the local area and take into account the needs of a wider range of service user groups, beyond older people alone.

- Recommendation 7: **Government should invest in local advocacy projects to support public engagement.** The national Fulfilling Potential Forum established in April 2014 to feed the user's voice into national policymaking should be replicated at the local level, supported by an additional £3 million in funding (equivalent to approximately £20,000 per health and wellbeing board area). We envisage that this investment in self-advocacy could also enable people with disabilities to make representations in other local policy areas, such as city deals.

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